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ABSTRACT

This paper first analyzes the situation of special needs education in the province of Kwazulu-Natal (South Africa) and then reports on qualitative research on three inclusive education initiatives in the province involving children with Down Syndrome at the primary school level. Current developments in the province include the continued existence of gross inequalities for children with disabilities and the continuation of separated special schools segregated by disability and race. Three case studies of children with Down Syndrome fully included in primary schools are described in terms of the characteristics of successful inclusion, such as a commitment to making it work with no particular preparation for inclusion; no constraint in views of what resources should be available; open-minded staff; vigilance, accountability, and advocacy; and suitable administrative and legislative arrangements. Priorities for children with Down Syndrome are discussed, including the need for valuation of diversity rather than normalization, information dissemination, and fostering of open views about the curriculum and curriculum development. (Contains 10 references.) (DB)

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THE INCLUSION OF CHILDREN WITH DOWN SYNDROME: A SOUTH AFRICAN EXPERIENCE

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THE INCLUSION OF CHILDREN WITH DOWN'S SYNDROME: A SOUTH AFRICAN EXPERIENCE

1. INTRODUCTION

The paper will firstly, present a critical analysis of current concerns and thinking in the field of special needs education in the province of Kwazulu-Natal. It will be argued that the study of disability issues cannot be divorced from the social and political context in which it is produced.

Secondly, the paper will present insights from qualitative research on three inclusive education initiatives in the province involving children with Down Syndrome at the primary school level. The focus will be largely on process issues, and implications for policy development.

2. CURRENT DEVELOPMENTS IN SPECIAL NEEDS EDUCATION

The field of special needs education in South Africa is fraught with unresolved issues and competing perspectives about what is involved and how change should proceed. It is clear that this is a time for re-organization in the country. Now that South Africa has entered a new era of democracy and non-discrimination, there is a complete re-assessment of the rights and the role of people with disabilities in our society.

The central government has tried to provide direction and facilitate change. In terms of the new Constitution people with disabilities are entitled to equal access to appropriate educational facilities, and shall not be discriminated against, directly or indirectly, on grounds

of their disability. Many of the policy documents that have emerged at the national level are viewed as enlightened (Report of the National Committee on the Organization, Governance and Funding of Schools, August 1995; Education White Paper 2: The Organization, Governance and Funding of Schools, February 1996; The South African Schools Bill, April 1996).

However, at the provincial level apartheid education is still in place. Gross inequalities in provision across the system continue to exist. There is an elaborate special education second system for White and Indian population groups with minor attempts to desegregate these schools and other facilities. Most African children with special needs are denied equal and appropriate educational opportunity. There has been little attempt in the province to address issues of inequity in funding and provision especially for rural children with disabilities, who historically have been the most discriminated against and marginalized group.

Many educators see reform as a proliferation of present practice, that is, large segregated special schools set up according to category of disability, remedial classes and units, and special self-contained classes for children with learning difficulties. This kind of provision has been based on western models of service delivery that are at present found to be inadequate in educating children full citizenship (Buckley, 1992; Dyson & Gains, 1993). Further, this model entrenches a deficit discourse, that is, specific problems are identified, appropriate structures have to be devised and resourced, solutions have to be worked out in advance, and specific problems have to be directed to appropriate structures (Dyson & Gains, 1993). There is little understanding of developmental issues - that learning and teaching should be seen as a process to be facilitated.

In the province, well resourced extremely high cost schools are centred around urban areas accessible only to a small and privileged section of the community. McConkey (1995) contends that the present model of education would absorb more than the total health and education budgets of most developing countries. As yet, in the province little attempt has been made to explore more economical approaches to meet the magnitude of need.

In many forums in the province, it is clear that disability issues are seen only in terms of special education and special schools. Often, disability issues are trivialized. Current debates do not include broader considerations such as education for the disabled as a human rights issue, a focus on quality of life, the right to equal access, the right to choice and education for citizenship. In many debates, individuals with disability are portrayed as victims, and have to be provided for by insulating and protecting them from society.

There is a tendency to stall for time using the argument that there has to be "climate making", that is, the need to make ready the system the system for children with disabilities. Discriminatory terms such as "selective inclusion", "responsible inclusion" are bandied about. There are also unrealistic demands for more and more resources.

Many of the arguments against more inclusive schools will not be used if the issue being addressed is other forms of diversity in schools, for example, language, class, gender, ethnicity etc.

3. INCLUSIVE EDUCATION INITIATIVES IN THE PROVINCE

In the face of all this, a few families have located schools that are prepared to act boldly, and

strive towards promoting education responsively rather than by anticipating and designing some proposed programme in advance.

One of the schools, the Ridge Primary School, is in the city of Pietermaritzburg at which two children with Down Syndrome are included. A second context is the Hillcrest Christian Academy, in a suburb called Hillcrest. The school has two pupils with Down Syndrome. The third school, Charles Hugo Primary, in Durban has a child with Down Syndrome in a special class. These initiatives are supported and fostered by the Down Syndrome Association of South Africa, a parent organization.

3.1 WHAT CHARACTERIZES THE WORKING INSTANCES OF INCLUSION IN THE PROVINCE?

3.1.1 Commitment to making it work:

Each of the inclusion initiatives had participants who were enthusiastic, and committed to fostering and sustaining the process. The decision to integrate the pupils was taken decisively. This attitude prevailed despite the fact that in one of the schools parents were told by an official from the education department:

"Your child is on trial for one month. If it does not work, the child will be transferred to a special school for severely handicapped".

At the Hillcrest Christian Academy and at the Ridge Primary School the general ethos at the school created a climate that was conducive to inclusion. A member of the school's management stated:

"We want our children to know that all children don't have to be the same height, shape, size, colour".

A teacher at one of the schools commented:

"We want our children to know that it is O.K. to be different. After all, we are preparing them for life and society."

The teacher at Hillcrest Christian Academy explained :

When we opened the school we decided that our policy would be to enrol children with disabilities. We, therefore, built ramps for wheelchairs at the outset. We decided that our school population will reflect the diversity in our society".

3.1.2 No sense of readiness:

There was no sense that the school had to work out in advance what had to be in place before embarking on an inclusion initiative. Teachers did experience initial apprehension with regard to their knowledge of children with disabilities and the skills that they needed to cope with the new challenges they faced. However, they were guided by the strong belief that they could cope, adjusting their expectations to the child's abilities and accepting their limitations. Staff worked within constraints and fine-tuned as they went along.

A comment from one teacher:

"The attention I give to A. (child with Down Syndrome) is the same I would give to a weaker child who required greater assistance".

3.1.3 Schools were not constrained by traditional/western views of what resources should be available.

Staff seem to work with a ethical naivety. As they go along, they work out to what extent it is desirable for the child to participate in the common curriculum. They

extent it is desirable for the child to participate in the common curriculum. They did not start by trying to water it down. In all the settings, the children are exposed to the energy and vitality of a full curriculum. It is interesting how few adjustments were made. There was no attempt to titrate the curriculum but teachers trusted the responsive of the child.

3.2 WHAT FACILITATES AND MILITATES AGAINST EFFECTIVE INCLUSION?

3.2.1 Open mindedness of staff:

A factor that facilitates an inclusive education initiative is the open minded of staff. There is a respect for children's rights, and an understanding of what an appropriate education really means in a developing country. They understand that the instances of inclusion really measure the appropriateness of education for all. One teacher remarked:

"Every child is different, whether the child has Down Syndrome or not and it is our responsibility as teachers teach them, to cater for every child".

The teacher at the Charles Hugo School explained how she experienced the placement of C., the child with Down's Syndrome in her special class.

"The psychologist brought C. one day four years ago and told me to keep her in the class for a week until appropriate placement could be found for her. I knew nothing about this condition. I included her in all activities in the class. The psychologist could not arrange for alternate placement within a week, and the week went into a month, and then a few more months. Then I just began teaching her and she began to learn. I soon realized that she has potential to learn. At that point I decided that I was not going to part with her. She has done so well .. reading and writing. She socializes very well not only in the special class but with all pupils in the school."

The school is planning to place C. in a mainstream class next year.

3.2.2 Vigilance, Accountability and Advocacy

Barton (1988) stresses that a critical analysis of power, control, vested interests, and decision making must be constantly called for and developed. Disability rights organizations such as the South African Federal Council (SAFCD) have an important role to play. The following issues need to be challenged:

To what extent are people able to exercise choice and control over their own lives?

Are the voices of parents and the disabled heard? Are resources locked into segregated special schools?

Can parents only obtain resource for their children only through placement in segregated special schools?

How can the needs of rural children with disabilities and their families best be met?

Parents need to be bolstered by disability rights organizations towards advocacy for their children. This is critical in our province especially in the case of African parents of children with disabilities. It is unfortunate that, often, professional groups who should be part of the vigilance are not prepared to work towards transformation.

An interesting development at the Ridge Primary School is that there is an impending lawsuit against the school by parents of one of the included children. Owing to behaviour problems the school came to the decision that the current placement for the child is not the most enabling and that the child needs more support than the school has the financial means to give. The parents have been advised to place the child at

a nearby special school. One of the problems at present is that the education department has not provided guidelines because of lack of formulation of policy and procedures. The education department is providing no support to the school or parent, and is not mobilized to support the process.

The point to be made is that parents have to be equally vigilant at wherever the site the child is educated. Parents have to ensure that the stress in the educational programme is on the quality of life of children with Down Syndrome. Parent Organizations affiliated to the South African Federal Council on Disability (SAFCD) are campaigning for a Parents' Charter that will outline the rights and responsibilities of parents of learners with special educational needs.

3.2.3 Administrative and Legislative arrangements:

As suggested earlier, policy documents at National level are enlightened. The South African Federal Council on Disability is an active participant at national level. Nationally, inclusive education has been accepted as a point of departure for policy development. However, the national policy initiatives are meaningless at the provincial level. Old apartheid thinking and structures are still entrenched. Funding is still disparate and this militates against change.

4. IDENTIFYING PRIORITIES FOR CHILDREN WITH DOWN'S SYNDROME

4.1 Normalization?

There is a need for policy makers, special educators, and mainstream teachers to

understand, that inclusive education is not about normalization. The disability sector opposes the view that society has to change people to make them more normal. It implies the removal of burden and shame through the achievement of normality. Oliver (1993) makes the point that the view of normalization is oppressive. The view that disabled people must strive to approximate the model of what is considered normal, where physical and social environments remain unchanged.

At a recent forum in the province, a special educator from the special schools constituency remarked:

"It would be an embarrassment to have a child with Down Syndrome in a high school".

The argument was that the best placement is a segregated special school.

Inclusive education implies that differences are not just tolerated but valued, and even celebrated, and where physical and social environments are constantly changing to accommodate and welcome these differences. Unfortunately, these critical issues are not part of the debate in our province.

4.2 Information Dissemination

There is a need to ensure that current and new insights from research on Down Syndrome children are disseminated. For example, one of the teachers at the school in Durban mentioned,

" I always thought that Down Syndrome children are severely mentally retarded and that they will never be able to read and write. I thought that we had to train them for a simple life."

There is a need for specialized information provided to schools. Organizations such as the Down Syndrome Association need to go beyond advocacy in a developing country. There is a need for simple resource bases to house information and ordinary schools need to network.

An important area that needs to be addressed is lack of community awareness about disability. At a parent support group meeting, the Thuthuko Group, run by the Down Syndrome Association and attended largely by African parents, the need to change community attitudes was seen by parents as critical the inclusion of their children in society. In the Zulu culture, a disabled child is viewed as a curse from ancestors. Children and their parents are not accepted and are isolated from the community. An attempt to start a support group in one of the townships failed because parents were reluctant to attend meetings for fear that people in the community would learn that they have a child with disabilities.

There are teachers who have suggested that the general public is reluctant to allow disabled children to learn side by side with non-disabled children. It has been suggested that parents believe that a child with disabilities will make demands on the teachers time, and hence other children would be disadvantaged. It is important that parents are educated on issues such as classroom organization, and curriculum development in an inclusive setting.

4.3 Views About the Curriculum and Curriculum Development:

The curriculum has to be seen as an open system rather than a fixed agenda or a course to be run (Prawat, 1992). Curriculum development has to be responsive and on going. Mrs W. Teacher at the Hillcrest Christian Academy commented that:

"Our curriculum is very flexible. We often respond to events around us. We do a lot of project work which leads to integrated studies across subject areas."

This particular teacher mentioned the occasion when an individual from the neighbourhood found a barn owl chick and brought the bird to the school. C., the child with Down Syndrome was so interested that she chose to undertake research on the barn owl. The result was a large chart with information on the barn owl that covered the various subject areas in the curriculum. C. was awarded a certificate at assembly for her work. The teacher mentioned that the whole class was then motivated to undertake research. Every child is now involved in a research project in an area of interest.

This view of the curriculum is in line with the recommendations in the National Curriculum Framework Document for the country recently released by the Department of National Education in December 1995. This policy document calls for an integrated curriculum involving cross curricular themes and topics for the first 9 years of schooling.

In all three settings, it is evident that teachers are committed to providing a broad and balanced curriculum, emphasizing the need to develop in children confidence and a positive self-image, as this they believe will help children deal with new experiences and demanding tasks in real life.

Western notions of IEP's and Statements will be increasingly superfluous in such learning contexts. The experience of educating children with Down syndrome in these three contexts suggests that children should be exposed to the fullness of the curriculum.

5. CONCLUSION

The issues raised in this paper and the processes that have emerged in the inclusive education projects researched have particular relevance for the transformation of special needs education policy and provision in the province. Exploring processes that have emerged provide useful indicators to how schools can organize their response to diversity. There is a need to use the experiences of participants in these initiatives to challenge our thinking and beliefs on what are appropriate policies and procedures to promote sustainable change in our province.

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